

Safe Sleep Summit Summary Report

Working together to eliminate inequities that contribute to unsafe infant sleep.



JANUARY 2025

In Appreciation

Thank you to everyone who participated in our inaugural Safe Sleep Summit. The event was a phenomenal success and a significant first step toward creating a roadmap for eliminating the inequities that contribute to unsafe infant sleep.

The goal of this report is to encapsulate the main ideas, issues, and opportunities that emerged during the Summit.

Our Summit—and this report—would not have been possible without the dedication and hard work of so many individuals. I'd like to especially thank Dr. Kyran Quinlan, a member of the Safe Kids Equity Advisory Council, who shared my vision for this Summit—and whose contributions to the planning and panels helped make it such a success. I also want to express my gratitude to Dr. Rachel Moon, an internationally recognized expert in infant sleep safety, for her contribution, and to the rest of the panelists, moderators, and the Safe Kids team.

Finally, a special thanks to all the academic researchers, family advocates, health care providers, manufacturers, public health practitioners, and policymakers, who so passionately shared their time and expertise. Having such a broad range of experience and insight in the room allowed us to identify key gaps, challenges, and potential innovations and partnerships. It also confirmed for us that together we can do more to make a greater impact and find solutions that help more families keep their infants safe during sleep. Our work is just beginning, and we are committed to continuing as a convener as we work together to make sure that all babies, in all communities, sleep safely.

With great appreciation,

Torine Creppy President, Safe Kids Worldwide





Introduction

On October 18-19, 2024, Safe Kids Worldwide convened a meeting of multidisciplinary professionals in Baltimore, Maryland to discuss the current burden and inequities of sudden unexpected infant death (SUID).ⁱ *The Safe Sleep Summit* brought together more than 150 professionals—including leading pediatricians, academic researchers, policymakers, public officials, members of child death review teams, health educators, product manufacturers, and child-welfare workers—to explore the persistent problem of sleep-related infant deaths. The goal was to begin to collectively create a roadmap to address existing inequities and, ultimately, to reduce the prevalence of unsafe infant sleep.

The day-long Summit consisted of four featured sessions, highlighting the overall issue of SUID; current challenges to prevention, particularly growing inequities; and potential solutions, including collaborative action. Sessions were a combination of styles, including presentation, panel discussion, and interactive group activities.

SESSION 1 Why Do We Need a Roadmap?

The goal of this session was to make a case for increased strategic investment in preventing SUID and in understanding existing inequities. It involved highlighting the issue from different professional perspectives, including gaps in knowledge, specific challenges to addressing inequities, and opportunities for enhancing prevention.

PANELISTS

Dr. Kyran Quinlan, pediatrician and public health advisor, SUID-Case Registry, Cook County, IL *Dr. Rachel Moon,* pediatrician, internationally recognized researcher in SUID, and chair of the American Academy of Pediatrics Subcommittee on Sudden Unexpected Infant Death *Dr. Abby Collier,* director, National Center for Fatality Review and Prevention

Dr. Melissa Pasquale, forensic pathologist, Connecticut State Office of the Chief Medical Examiner

SESSION 2

How Do We Meet Families Where They Are?

The goal of this session was to provide examples of current programmatic approaches; to show how they can contribute to addressing inequities; and to discuss the pros and cons of a harm-reduction approach and its implications for education and educator preparation.

PANELISTS

Bridget Guassa, chief operating officer, Cribs for Kids
Sinmidele Badero, fatality review coordinator, B'More for Health Babies, Baltimore City Health
Department
Alison Jacobson, chief executive officer/executive director, First Candle
Felicia Tillis-Clark, prevention coordinator, Community Partnership Approaches for Safe Sleep (CPASS),

Chicago

Jessica Ritter, (moderator), state office coordinator, Safe Kids Pennsylvania



SESSION 3

How Do We Build a Systems Approach to Safe Sleep?

The goal of this session was to provide perspectives on how to build, strengthen, and sustain a systems approach to safe sleep. Presentations and discussions covered current legislative processes, equipment and technology challenges, parent advocacy, and the need to ensure we meet the needs of all families.

PANELISTS

Dr. Jonathan Midgett, consumer ombudsman, Consumer Product Safety Commission (CPSD)

Dr. Sam Hanke, president, Charlie's Kids

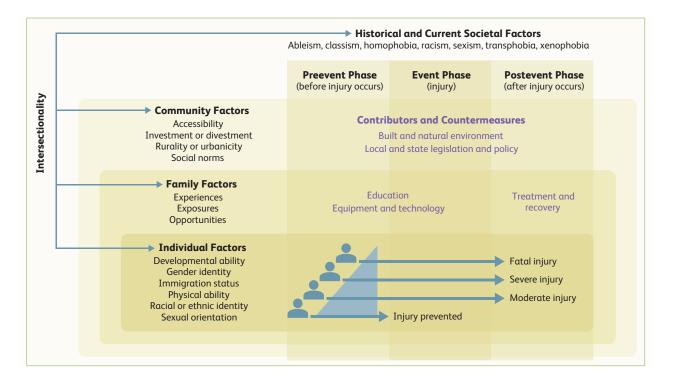
Nancy Cowles, executive director, Kids in Danger (KID)

Dr. Stacy Scott, (moderator), vice president of Health Equity Innovation, National Institute for Children's Health Quality (NICHQ)

SESSION 4 The Kendi-Macy Injury Equity Framework

Dr. Sadiqa Kendi, Safe Kid's Chief Medical Officer, introduced the Kendi-Macy Injury Equity Frameworkⁱⁱ which provides a theoretical basis to guide systematic data collection and analysis of the complex, multilevel structural factors at the root of injury inequities, and the design of innovative interventions to address them. Dr. Kendi's presentation was followed by small group discussions where participants engaged in a modified pediatric injury equity review (PIER)ⁱⁱⁱ process, using a representative SUID example to identify additional factors impacting SUID inequities, current gaps, and potential actions.

This report summarizes the Summit discussions, highlighting key points raised about the problem, challenges facing the field, and potential solutions. It is designed to serve as a starting point for creating a national road map for collaborative action.





The Problem

Current Burden and Trends

- The rates of SUID in the U.S. are at unacceptable levels and it is the leading cause of death for children between 1 month and 1 year of age.^{iv}
- In 2022, there were 3,700 cases of SUID, the equivalent of more than 10 deaths each day of the year. That average daily number among infants under one year was almost as high as the average daily number of deaths from motor vehicle crashes among all children ages 0-19 years.^{iv}
- SUID rates plateaued in the 2000s after encouraging decreases over the previous decade when the American Academy of Pediatrics (AAP) introduced its safe sleep recommendations and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) launched the Back to Sleep campaign. Since 2020, SUID rates have been increasing again. In fact, the 2022 rate of 101 deaths per 100,000 live births is the highest since 1996.^v

Inequities

- Rates of SUID across the country vary greatly, with state rates ranging from 45.0 cases of SUID per 100,000 live births in Massachusetts, and five times that rate (221.9/100,000) in Mississippi.^v
- There are large disparities in SUID rates by race, with the highest rates among non-Hispanic Black and non-Hispanic American Indian and Alaskan Native infants. Those groups, along with infants in rural areas, have the highest SUID rates in the country.^v
- Studies of urban populations have found higher SUID rates in both non-Hispanic Black and Hispanic populations compared to the national average. Black/White disparities are magnified in large U.S. cities. Hispanic rates are typically higher than White rates in large U.S. cities which is not the national pattern. Populations that experience higher rates of SUID tend to have multiple risk factors, which may be linked to economic hardship and housing insecurity.^{vi}

Contributing Factors

In addition to identifying trends and inequities, presentations highlighted several unsafe sleep factors contributing to SUID. These are illustrated by the results of a 2007 study^{vii} shared by Dr. Pasquale that identified:

- More than 50% of SUID deaths occurred on adult beds (with and without bedsharing)
- More than 80% of deaths in adult beds also involved bedsharing
- More than 10% of SUID deaths occurred on couches
- About 30% of SUID deaths occurred in cribs (including bassinets and portable cribs)
- In 57% of SUID deaths that occurred in a crib, at the time they were found the infant was either prone and face down with obstruction of the nose and mouth (42%) or prone with partial or no blockage (15%); 40% of infants were found on their backs, and 3% on their side
- SUID deaths were found to peak at 2 months of age



Dr. Moon also noted that current AAP recommendations for safe sleep are designed to address the triple risk model for sudden infant death syndrome (SIDS) put forward by Filiano and Kinney.^{viii} This model describes the interplay between infant arousal defects caused by brainstem dysfunction, gene polymorphism and prenatal tobacco/drug exposure, an environment that can lead to asphyxiation (e.g., prone/side sleep position, bedsharing, soft bedding) and a critical development period for homeostatic control between 2-4 months. The AAP recommendations address this model (see table below).^{ix}

Recommendation	Infant Arousal	Decrease risk of asphyxiation
Back to sleep for every sleep	\checkmark	\checkmark
Use a firm, flat, non-inclined sleep surface to reduce risk of suffocation or wedging/entrapment		\checkmark
Feeding human milk is recommended because it is associated with a reduced risk of SIDS	\checkmark	
It is recommended that infants sleep in parents' room, close to the parents' bed, but on a separate surface designed for infants, ideally for at least the first 6 months	\checkmark	\checkmark
Keep soft objects, such as pillows, pillow-like toys, quilts, comforters, mattress toppers, fur-like materials, and loose bedding, such as blankets and nonfitted sheets, away from infant's sleep area to reduce risk of SIDS, suffocation, entrapment/wedging, and strangulation		\checkmark
Offering a pacifier at naptime and bedtime is recommended to reduce the risk of SIDS	\checkmark	
Avoid smoke and nicotine exposure during pregnancy and after birth	\checkmark	
Avoid alcohol, marijuana, opioids, and illicit drug use during pregnancy and after birth	\checkmark	
Avoid overheating and head covering in infants	\checkmark	\checkmark



Challenges



Data to inform the issue are incomplete

Having good data is critical to inform the development and evaluation of preventive messaging, educational approaches, product safety, and policy. Currently, population-level data on SUID are limited. Vital statistics provide information on the incidence of SUID, but those data do not provide contextual information about the deaths. The National

Center for Fatality Review and Prevention's National Fatality Review Case Reporting System (NFR-CRS), which provides additional contextual information on SUID deaths through infant death reviews, is not population based. Further, not all jurisdictions contributing to the NFR-CRS use the more detailed *sudden unexpected death investigation reporting form* (SUIDIRF) and the level of missing data varies greatly. The SUID Case Registry (SUID-CR), which is led by CDC's Division of Reproductive Health, uses the NFR-CRS and the SUIDIRF and therefore has the richest data on SUID, particularly for the circumstances preceding the death. However, the SUID-CR currently only captures 40% of SUID cases in the U.S. Further, it is not easily accessed.

Sudden Infant Death Investigation, which collects the most complete information including death-scene reenactment, can provide vital details to help discern SUID cause. However, achieving a high-quality investigation is challenging, and there is often a lack of certainty to meet the burden of proof for asphyxia. Consequently, in the absence of additional information, many cases that may well be accidental suffocation or strangulation in bed are labeled as SIDS or undetermined. Further, legislative mandates and enforcement of infant death review, including death-scene reenactment, vary greatly from jurisdiction to jurisdiction.



Meeting families where they are and supporting behavior change

It is difficult to definitively discern why SUID rates plateaued and why they remain so high. While following the ABCs (Alone, on their Back, in a Crib) has been shown to reduce SUID, it has been challenging to effectively promote the practice, particularly among groups at

highest risk. What's more, even when families are aware of recommended safe sleep practices, research shows they do not always follow them.

There are myriad reasons that families do not follow recommended practices, including preference for cosleeping; convenience on the part of exhausted new parents; and lack of space and resources to provide a safe sleep environment for a baby. Some of these reasons are influenced by cultural norms and individual level factors, such as attitudes and perceived control. Where inequities are greatest, the reasons are further upstream with risk consistently related to poverty and marginalization that result in families having significant burden from a variety of unmet social needs.

One significant point raised during the Summit was parents' perception of the level of risk associated with an unsafe sleep environment and the fact that public awareness of the risk of suffocation issue is low, both of which may impact behavior.



Regardless of the reasons for unsafe sleep behavior, it was noted that current prevention efforts are falling short of meeting the needs of all families, and thus innovative thinking is needed. A risk reduction approach to safe infant sleep was discussed, with agreement that this approach may be necessary for one-on-one education with families as part of meeting them where they are, and in understanding barriers and finding solutions to reduce hazards in a given context. But there was also agreement that this approach should not be used in public awareness campaigns, which should continue to follow the AAP guidelines. It was noted that, while risk reduction is a common approach in public health and injury prevention, there is limited research into this approach in the area of safe sleep, suggesting the need for further exploration.



Limited public awareness and lack of a systems-level response

Public awareness of the problem remains a challenge. These deaths almost never make the news.^x The loss of an infant to SUID is devastating for a family, and they are often consumed by grief and shame, and understandably unwilling to share their story publicly.

Further, it can take weeks or months for a definitive cause of death to be determined, so the likelihood of news coverage is not the same as an immediate and public death, such as a car crash that kills an infant. The loss of life of young children in car crashes in similar numbers led to a broad systems response to the issue more than 20 years ago, which has resulted in major reductions. A similar response has not occurred with SUID.





Potential Actions to Build Equitable Systems and Reduce the Burden of SUID

As Summit participants discussed the current challenges and evidence gaps, there were several key points of agreement, and a number of potential solutions were put forward. There was agreement that it was important to meet families where they are and acknowledgement of the profound impact of SUID on a family and the community. These two points underlined the urgent need to work together from prevention through to treatment and recovery when tragedies occur. Achieving that demands a holistic and interdisciplinary systems approach with action at all levels of the socioecological framework, similar to the approach taken for other important public health issues. It also demands a better understanding of the broader context through data and human insight, particularly with respect to building equitable systems to protect vulnerable infants from sleep-related deaths and to reduce the burden of SUID. The Kendi-Macy Injury Equity Framework was viewed as a useful tool in ensuring inequities were considered as that broader context and potential solutions were explored.

The potential solutions put forward during the discussions are presented below, grouped by countermeasure and in no particular order:

LEGISLATION AND POLICY

- Enhance training for medical examiners to strengthen death scene investigations.
- Enhance death investigations, including using the CDC's sudden unexpected death investigation reporting form.
- Expand the CDC's case registry to include all SUID deaths by advocating for additional funding.
- Develop a universal infant safe sleep checklist for distribution by all services touching expecting families and families with infants.
- Advocate for paid family leave (postpartum leave) for at least the first 6 months or year of infant life.
- Develop universal in-home nurse visiting programs for all new parents to eliminate bias in who is offered a visit.
- Provide free safety education with a universal message.
- Build a coordinated, collaborative response to safe sleep at the local level that includes health care professionals, public health, community health, social work, and home visiting organizations.
- Introduce policies to ensure messengers are modeling the recommended practices (e.g., hospitals, daycare centers, etc.).
- Train all first responders to observe infant sleep spaces when called for other non-urgent issues.



BUILT ENVIRONMENT

- Develop guidance and strategies to address lack of safe sleep environments for families experiencing homelessness or houselessness (both of which can occur in a variety of situations).
- Mandate that all services that touch expecting families and families with infants, and particularly families facing housing instability, include the provision of information and resources related to renter's rights.
- Introduce policies requiring shelters to auto-enroll expecting families and families with infants into services rather than expecting them to know where and how to enroll.

SAFETY PRODUCTS & EQUIPMENT

- Undertake research to better understand how families use safe sleep products.
- Ensure products are safe (even when people do not use them correctly) through legislative and regulatory efforts and education.
- Support public policies to identify and root out unsafe counterfeit products marketed for infant sleep.
- Find more effective ways to encourage reporting of unsafe products on the market to saferproducts.gov.
- Encourage continuous messaging to consumers from manufacturers on product recalls. The outreach should be as vigorous as efforts made when new products are marketed.
- Introduce QR codes on all baby equipment that links families to information on how to use products and on product recall registration.
- Explore the use of artificial intelligence (AI) to allow consumers to take a picture of a product and receive information on whether it has been recalled.
- Introduce pop-ups on marketplace/resell websites that warn consumers about recalls.
- Encourage point-of-sale education around safe sleep.
- Explore a way to "recertify" used products.
- Develop consensus on messaging around products and equipment to reduce inconsistent messaging.

EDUCATION AND AWARENESS RAISING

- Explore ways to increase risk perception of SUID.
- Undertake research to inform enhanced educational approaches for families, including exploring whether focusing on suffocation as the key risk for SUID or changing the definition of a baby who is a "good sleeper" would help change behavior.
- Explore behavior-change models to better understand why educators and families do not always follow recommended practices.
- Enhance guidance and educational approaches for educators, particularly with respect to working with populations at increased risk of SUID.



- Enhance educational approaches for populations at increased risk of SUID by co-creating culturally sensitive and specific messages and resources with trusted voices.
- Ensure consistent messaging using language, photos, and images that promote the recommended practices as the social norm.
- Create a mechanism to capture existing programs, resources, etc. in one place, with the goals of reducing duplication of effort and making it easier for educators to find existing data-driven and evidence-based information.
- Encourage one-on-one education that starts with understanding current sleep environment and barriers and uses a problem-solving approach to build self-efficacy (for example, do not be scared, be prepared).
- Explore how to effectively tell the story of SUID to the public to increase their awareness of the issue and change risk perception, including engaging with diverse families willing to share their stories.

TREATMENT & RECOVERY

- Ensure all neighborhoods have acceptable response times for Emergency Medical Services (i.e., time it takes for a responding EMS unit to arrive at the scene of an emergency).
- Undertake a landscape review to understand existing support for families who lose a child to SUID.
- Build systems of support for families who lose a child to SUID among people who families trust, such as church leaders, community agencies, and social workers.
- Ensure bereavement services are tailored to each family, and are responsive to that family's needs.

Next Steps

The 2024 Safe Sleep Summit was successful in bringing together professionals from different sectors and disciplines to discuss the problem, current challenges, and potential solutions, particularly with respect to examining structures and systems that create and perpetuate the persistent and unacceptable inequities contributing to unsafe infant sleep. Attendees agreed collective action is necessary to eliminate the inequities that contribute to unsafe infant sleep. As such, the Summit was an important first step in encouraging a more coordinated approach to SUID prevention. However, there is much work to be done.

Safe Kids Worldwide is committed to acting as a convener in supporting the creation of the much-needed roadmap toward eliminating inequities in safe-sleep practices and in reducing the rate of SUID. Following the Summit, Safe Kids Worldwide is undertaking an initial partnership analysis to understand all those who have a stake in the issue, particularly those who did not attend the Summit. In early 2025, Safe Kids plans to establish "working groups" that will offer opportunities for input and feedback to prioritize and then flesh out next steps related to the potential actions coming out of the Summit. We are committed to working together so we can achieve measurable and meaningful change.



ENDNOTES

- Sudden unexpected infant death is a sudden and unexpected death of a baby aged younger than 1 year. For these deaths, there is no obvious cause before investigation. Sudden unexpected infant deaths often happen during sleep or in the baby's sleep area.
 Reporting of SUID includes sudden infant death syndrome (SIDS), accidental suffocation and strangulation in bed, and other deaths from unknown causes. (Source: CDC)
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